

Presented by Grand Valley State University



# The Ethics of Physician Assisted Death

Generously underwritten by  
The Richard & Helen DeVos Foundation

[www.gvsu.edu/colloquy](http://www.gvsu.edu/colloquy)

This Colloquy series is made available via live webcast to the general public and to any organization or class that wishes to view the Colloquy from an offsite location. The link is available on the Colloquy website.

[www.gvsu.edu/colloquy](http://www.gvsu.edu/colloquy)

## **Dr. Robert Arnold, MD**

Distinguished Service Professor of  
Medicine

Chief, Section of Palliative Care and  
Medical Ethics

Director, Institute for Doctor-  
Patient Communication

University of Pittsburgh School of  
Medicine

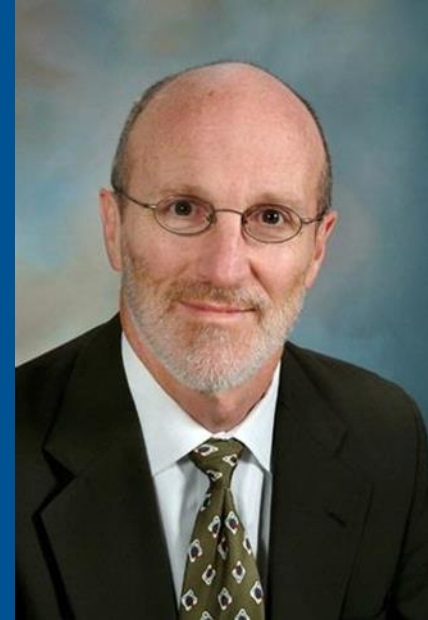
Medical Director, UPMC Palliative  
and Supportive Institute



## **Dr. Timothy Quill, MD**

Georgia and Thomas Gosnell  
Distinguished Professor  
in Palliative Care

Professor of Medicine, Psychiatry and  
Medical Humanities, Palliative Care  
Division, Department of Medicine  
University of Rochester School of  
Medicine



Our **generous sponsor** for tonight's event is The Richard & Helen DeVos Foundation, and they have disclosed to us that they have no commercial conflict of interest in their donation.

Our format will be changed just a bit tonight. Our speakers have collaborated to base their presentations on a case study video. Dr. Quill will present the case study and then each of the speakers will present their views on tonight's topic. Following this Dr. Reitemeier will moderate a one hour period of questions and answers.

There are **question cards** in your folders; you can fill these out as you listen to the presentations and pass them to the outside aisles where our volunteers, Sara Walker and Sandi Leyder, will collect them and deliver them to Dr. Reitemeier. He will begin the dialogue with some of the written questions and then, during the last twenty minutes of the evening, he will open the floor to verbal questions from the audience.

When you **raise your hand**, our volunteers will come around with a portable microphone: please speak clearly as the event is recorded and transcribed for publication. Also, make your questions brief, so as to allow everyone a chance to interact with the speakers.

For those of you here in the room with us, the instructions for claiming CME credit for tonight's presentation have been included in your folder. The procedure requires that you complete an evaluation on-line through Grand Rapids Medical Education Partners website. The only thing you have to do tonight is sign in for CME credits at the registration table which we hope you have already done. Tonight's presentation will allow you to claim 2 CME credits.

We do ask that everyone complete the white Colloquy evaluation forms that are in your packets. Please note that on this answer scale, you are strongly disagreeing when you circle number 1, and strongly agreeing when you circle number 4.

This auditorium contains **T-Loop technology** for the hearing impaired, so if you are wearing a compatible hearing aid, please turn this feature on for greater sound clarity.

And now... kindly turn your telephones and pagers to silent mode. I invite to the podium Dr. Paul Reitemeier, the moderator for this evening's Colloquy.

Presented by Grand Valley State University



# The Ethics of Physician Assisted Death

Paul Reitemeier, PhD

Corporate Director, Clinical Ethics, Beaumont Health

(Moderator)

# Ethics of Physician Assisted Death

Bob Arnold MD

University of Pittsburgh

Timothy Quill

University of Rochester Medical Center

# Potential Conflicts of Interest

Neither Dr. Arnold or Dr. Quill have any financial conflicts of interest with regard to this topic.

Both Dr. Arnold and Dr. Quill have been advocates for broader access to palliative care and hospice for all seriously ill patients.

Dr. Quill has been an advocate for more open access to physician assisted death for many years.

# Case Presentation

Tim Quill

# Fear About the Future

# The Clinical Question

Bob Arnold

# PHYSICIAN-ASSISTED DEATH

## *Main Elements*

Physician provides means at patient's request

Patient must carry out final act

Potential escape is important to many

Physician moral responsibility as an accomplice

Synonyms include:

- *physician-assisted suicide*
- *physician aid-in-dying*

# VOLUNTARY ACTIVE EUTHANASIA

## *Main Elements*

Physician both provides the means and carries out the final act

Requires request and consent from a competent patient

Physicians more reluctant about this than PAD

Requires physician presence at the time of death

Allows a response to a wider range of suffering than PAD

Illegal in US and much more likely to be prosecuted than PAD

# Physician experience

20-50% of patients are asked about PAD

- Oncologists slightly higher

# Patients who ask for PAD

Mainly cancer patients

Largely middle-higher SES, white

Issues largely have to do with control and dependency

- Depression, hopelessness are more common

# Some Data from Oregon

(Tolle S et. al. J Clin Ethics. 2004; 15:111-8)

1/300 deaths by PAD

1/50 talk with their doctor

1/6 talk to their families

*MOST PEOPLE WANT TO TALK*

*VERY FEW ULTIMATELY ACT*

# Limiting PAS: Palliative care and hospice as medical norms

Recent phenomenon

Limited access to palliative care

Hospice regulations limit ability access

# Limitations of Palliative Care:

Background Prevalence of Unrelieved Pain in Terminally Ill

Bonica: Ordinary care 32-80%

Hospice or palliative care 8-37%

# Limitations of Palliative Care:

Data about Unrelieved Pain at Death on Hospice

Bruera (Edmonton): 15-37% “poor” pain control

Ventafrieda (Milan): 35% “uncontrolled” pain

Moulin/Foley (NY): 27% “poor” control

Parks (St. Christopher): 8% “severe/unrelieved” pain

NHO: 21% “severe” pain 2 days prior to death

# Why might these options be important?

Reassurance for witnesses of bad death

Potential escape when suffering unacceptable

Awareness of potential options important to some patients, families, and caregivers

# Potential Last Resort Options

Accelerating opioids to sedation for pain  
Stopping life-sustaining therapy

Voluntarily stopping eating and drinking  
Palliative sedation

Physician-assisted death  
Voluntary active euthanasia

# Accelerating Opioids for Pain

## *Main Elements*

Opioids mainstay in severe pain management

Dose is proportionate to level of pain

Small risk of sedation, respiratory depression, death with very high doses or sudden change

Risk is minimal in usual pain management

Death, if it comes, is unintended

# Stopping Life-Sustaining Therapy

## *Main Elements*

Potentially life-sustaining Rx include:

- Mechanical ventilation
- Renal dialysis
- Feeding tube; intravenous fluids
- Implantable defibrillator
- Steroids; usual disease-treating measures

May be withheld, or withdrawn once started

Decision-making by patient if capable, or by family if incapacitated (*based on substituted judgment*)

# VOLUNTARILY STOPPING EATING AND DRINKING

## *Main Elements*

Result of active patient decision

Patient physically capable of eating

Requires considerable patient resolve

Takes one to two weeks

Theoretically does not require physician involvement

Symptom management as process unfolds

# PALLIATIVE SEDATION

## *Main Elements*

Sedation potentially to unconsciousness, life-supports withheld

Uses benzodiazepines or barbiturates

Process usually takes days to weeks

Patient dies of dehydration or complication

Patient unaware of suffering

Combination of “double effect” and withholding life-sustaining therapy

# What if a patient asks me about PAD?

Take a deep breath

- The role of your own emotion
- Rather than turn into a yes/no, be curious about the situation
- View the conversation as a way to build a relationship

# Will you help me die?

## *Now or in the future?*

Many patients may be reassured by the possibility

- *Gives a sense of control and possibility*
- *Help them prepare for the future*

A relatively small number will eventually want to activate

- *Why now?*

# Reassurance about the future

Commitment to be guide and partner

Explore hopes and fears

- *What are you most afraid of?*
- *What might death look like?*

Commitment to face worst case scenario

Freedom to worry about other matters

# Talking about PAS now

Assess competency

Assess ways to improve palliative care

- Symptoms – physical and psychological
- Suffering
- Depression

Think about social support and awareness

# Talking about PAS now

Be aware of the legal environment

Think about the ethical and psychosocial impact for you

Get support and help

# Ethical issues

# Arguments for PAD

Autonomy

Mercy

Non-abandonment

# Arguments for PAD

Lack of difference between PAD and forgoing life sustaining treatments

- Lack of difference between acting and stopping
  - Ventilator care
- All the risks of PAD could apply to forgoing life sustaining treatment

# Arguments against PAD

Intentional acts to shorten a life are wrong (killing)

May scare patients and seem like we are urging them to end their life

Could undermine palliative care because of public controversy (death panel)

Slippery slope

Undermine the profession

# Rule of Double Effect and PAD

Intent has to be good

Bad effects can be foreseen but not intended

Proportionality – Suffering must be severe enough to warrant the risk

Bad effect cannot be the means to the good effect

# Rule of double effect –some challenges

Unclear how we evaluate intent and ignore philosophy of causality

Common last resort scenarios...

- Palliative sedation (clinician/patient intent is to escape suffering)

***What happens when a patient's intent is to die earlier?***

# Other questions that are coming up

Social inequality and implications for PAD

How does lack of good palliative care affect PAD

- Where should we spend our energy as a society

What about the issues that others are facing who have done this longer

- Children, incapacitated patients and dementia

# Current State of Practice

Tim Quill

# What do Terminally Ill Patients Say? Considering versus Pursuing PAD

988 terminally ill outpatients (except AIDS)

- 60% support PAD
- 10% seriously considering PAD

92 terminally ill inpatients (Calvary hospice)

- 17% had a high desire for PAD

# Who Asks About Physician-Assisted Dying?

Patients with cancer, neurologic disease, AIDS

White

Western culture

Have medical coverage

Most have access to hospice

# Some Data from Washington State

## Motivations for Seeking a Hastened Death

### *Illness-related experiences*

- Feeling weak, tired, uncomfortable (69%)
- Loss of function (66%)
- Pain or unacceptable side effects of pain meds (40%)

### *Threats to sense of self*

- Loss of sense of self (63%)
- Desire for control (60%)
- Long-standing beliefs in favor of hastened death (14%)

### *Fears about the future*

- Fears about future quality of life and dying (60%)
- Negative past experience with dying (49%)
- Fear of being a burden on others (9%)

### *IT AIN'T PAIN, AND IT AIN'T SIMPLE*

(Pearlman / Starks in Physician-Assisted Dying .2004 J Hopkins Press 91-101.)

# Other ethics/public policy issues

In Oregon PAD legislation associated with improved eol care

- High percentage of deaths at home
- High rates of hospice referral before death
- Relatively strong opioid prescribing
- State-wide approach to DNR/DNI (POLST)

A wake-up call to physicians

- Physicians attend POLST and palliative care training
- Strong physician commitment to palliative care

# Physician Assisted Death in US: Legalization in Six States

Oregon by referendum

Washington State by referendum

Montana by constitutional challenge

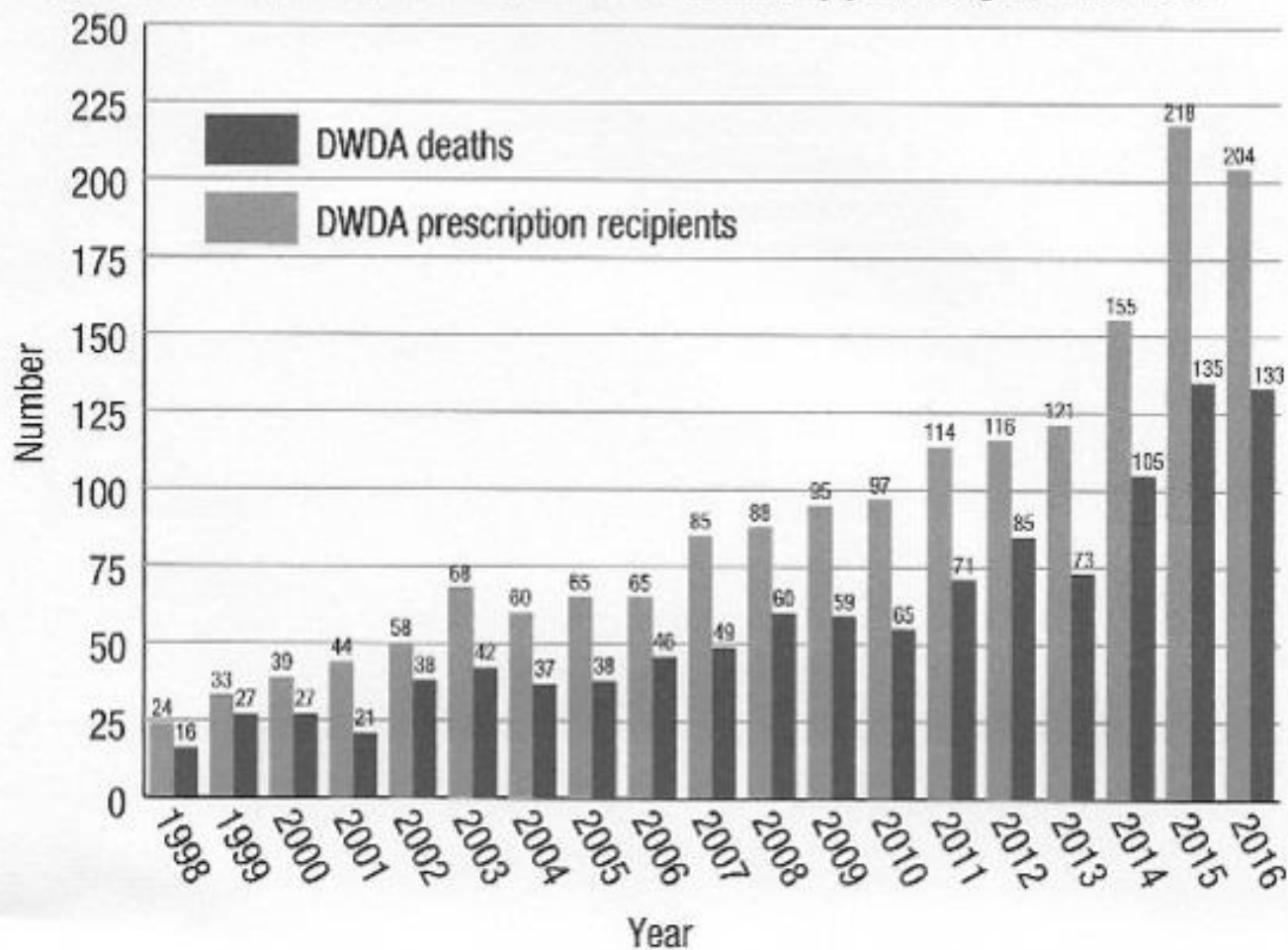
Vermont by legislative action

California by legislative action

Colorado by referendum

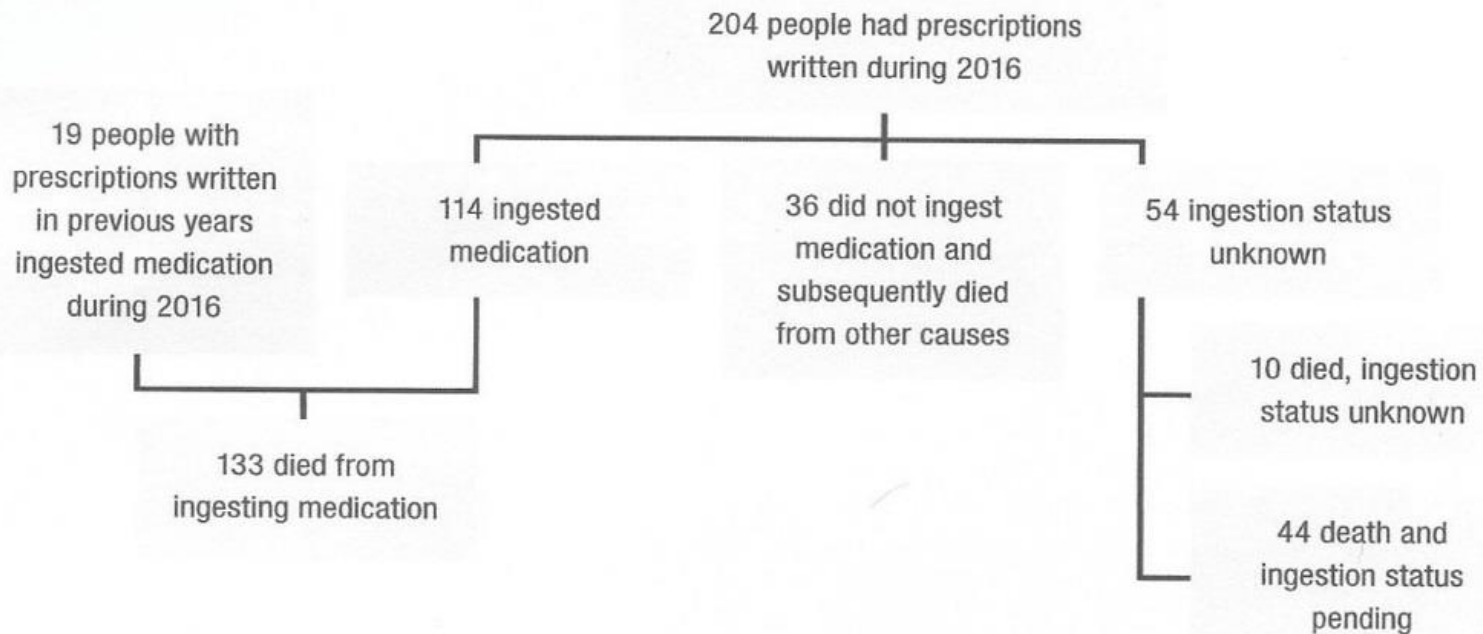
*Under active consideration in Washington DC*

Figure 1: DWDA prescription recipients and deaths\*, by year, Oregon, 1998–2016



\*As of January 23, 2017

**Figure 2: Summary of DWDA prescriptions written and medications ingested in 2016, as of January 23, 2017**



<sup>1</sup> Rate per 10,000 deaths calculated using the total number of Oregon resident deaths in 2015 (35,709), the most recent year for which final death data are available.

# ADDITIONAL PAD OREGON DATA

- Most patients white (96%)
- Almost all had insurance (99%)
- Most had cancer (80%)
- Most relatively well educated (75% some college or more)
- Records cite battles against underlying diseases
- 90% enrolled in hospice programs (all had access)
- Uncontrolled pain not the main motivating factor
  - *Autonomy, lack of enjoyment, loss of dignity*
- Relatively stable, very low rates over 15 years

# Physician Assisted Death in Canada

## Canadian Supreme Court

- Fundamental Right to choose physician assisted death
- Potentially includes either PAD or VAE

## Criteria included

- “Grievous and irremediable medical condition...”
- “Causes enduring suffering that is intolerable to the individual”

Enacted June 6, 2016

**Legal status of physician assisted dying (PAD) and voluntary active euthanasia (VAE) in other countries as of June 2016**

Country	Legal status of PAD and VAE
Netherlands	PAD and VAE legal for adults and competent children older than age 12
Belgium	PAD and VAE legal for adults; euthanasia permitted for terminally ill children of any age
Luxemburg	PAD and VAE legal for adults and children older than age 12
Columbia	PAD and VAE legal for adults
Germany	Assisted suicide (not by physicians) is legal for competent, uncoerced adults, but the German Medical Association prohibits physicians from assisting on grounds that they have a duty to rescue
Canada	PAD and VAE legal for adults, subject to guidelines established under directive from the Canadian Supreme court as of June 6, 2016
Switzerland	Assisted suicide legal for adults if performed by someone with no direct interest in the death; some clinics will accept nonresidents

PAD: Physician-assisted dying; VAE: voluntary active euthanasia

# Summary: Current State of Practice

What currently counts the most?

- Where you live
- Values of your physician
- Willingness of your physician to take risks
- Particular nature of your condition

What should count the most?

- Values of the patient
- Availability of hospice
- Presence of unacceptable suffering despite hospice
- Values of the participating physician

# Some Key Policy Questions

# INTERLOCKING PUBLIC POLICY QUESTIONS

How to improve access to and delivery of palliative care services to all dying patients?

How to respond to those infrequent, but troubling patients who are dying badly in spite of excellent care?

Should we respond to individual cases or create public policy?

# PALLIATIVE OPTIONS OF LAST RESORT

## *The Need for Safeguards*

Protect vulnerable from error, abuse, coercion

Ensure access and adequacy of palliative care

Risks cited for PAD are also present for other last resort options

Balance flexibility and accountability

Balance privacy and oversight

# PALLIATIVE OPTIONS OF LAST RESORT

## *Categories of Safeguards*

Palliative care accessible and found to be ineffective

Rigorous informed consent

Diagnostic and prognostic clarity

Independent second opinion

Documentation and review

# Risks of “*Don’t Ask, Don’t Tell*” Policy

Access uneven and unpredictable

Discourages explicit conversation

Risk of misunderstanding

No safeguards to ensure adequate palliative care and adequacy of evaluation

Potential bereavement problems with secrecy

# Potential Risks of Being Explicit about Last Resort Options

Might frighten some patients

Might lead to pressure to prematurely choose death

Might undermine progress in hospice and palliative care

Might undermine fundamental physician values

# Advantages of Being Explicit about Last Resort Options

Acknowledges the problem

- Less patient and family fear
- Free energy for other more important tasks

Reinforces the physician imperative to be responsive

- Nonabandonment
- Get help if you need it!

In Oregon, most patients want to talk; very few act.

- 1/300 die using PAS
- 1/50 talk to their doctor
- 1/6 talk to their families

# Physician Assisted Death and other Last Resort Options

*The Bottom Line*

Only sensible in context of excellent palliative care

Currently, last resort options unevenly / unpredictably available

All options should be subject to similar safeguards

Open processes are ultimately more safe, predictable, and accountable than secret processes

# Physician Assisted Death and other Last Resort Options

## *The Bottom Line*

Clarity about which options are available, and under what circumstances, would be beneficial

- Reassure those who fear a bad death
- Increase responsiveness to extreme suffering
- More ability to address unique circumstances
- More accountability when suffering persists

Return to Our Patient

# Rethinking End-of-Life Options

## Selected References

- Quill, T.E., *Death and dignity: A case of individualized decision making*. N Engl J Med, 1991. **324**: p. 691-694.
  - Quill, T.E., *The ambiguity of clinical intentions*. N Engl J Med, 1993. **329**: p. 1039-1040.
  - Quill, T.E., *Doctor, I want to die. Will you help me?* JAMA, 1993. **270**: p. 870-873.
  - Quill, T.E. and R.V. Brody, *"You promised me I wouldn't die like this". A bad death as a medical emergency*. Arch Intern Med, 1995. **155**: p. 1250-1254.
  - Quill, T.E. and C.K. Cassel, *Nonabandonment: A central obligation for physicians*. Ann Intern Med, 1995. **122**: p. 368-374.
- Quill, T.E., R. Dresser, and D.W. Brock, *Rule of double effect: A critique of its role in end-of-life decision making*. N Engl J Med, 1997. **337**: p. 1768-1771.

## More Selected References

- Quill, T.E., Lo, and D.W. Brock, *Palliative options of last resort: A comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia*. JAMA, 1997. **278**: p. 1099-2104.
- Quill, T.E., et al., *The debate over physician-assisted suicide: Empirical data and convergent views*. Ann Intern Med, 1998. **128**: p. 552-558.
- Quill, T.E., B. Coombs-Lee, and S. Nunn, *Palliative options of last resort: Finding the least harmful alternative*. Ann Intern Med, 2000. **132**.
- Quill, T.E., *Dying and decision-making -- Evolution of end-of-life options*. N Engl J Med, 2004. **351**: p. 562-563.
- Quill, T.E. , *Physician-assisted death in the United States: are the existing "last resorts" enough?* Hastings Center Report, 2008. **38**(5): p. 17-22.
- Quill, T.E., et al., *Last-resort options for palliative sedation*. Annals of Internal Medicine, 2009. **151**(6): p. 421-4.

# Q & A

[www.gvsu.edu/colloquy](http://www.gvsu.edu/colloquy)

Presented by Grand Valley State University



Presented by Grand Valley State University

**MARK YOUR CALENDARS!**

**October 16, 2017**

# **The Ethics of Medical Choice - Rationing**

**Dr. Steven Teutsch, MD, MPH**

Adjunct Professor, Fielding School of Public Health, UCLA

Former Chief Science Officer, Los Angeles County Public Health

**Dr. Susan Dorr Goold, MD, MHSA, MA**

Professor of Internal Medicine, Medical School

Professor of Health Management and Policy, School of Public Health

University of Michigan

[www.gvsu.edu/colloquy](http://www.gvsu.edu/colloquy)